



2022

**CdLS Foundation
Annual Report**



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.



THE FUTURE LOOKS BRIGHT AT THE CdLS FOUNDATION

Dear Friends,

I hope this message finds you well. I am grateful for your incredible support over the past year.

Thanks to your generous donations, we hosted a virtual conference featuring critical topics of interest for our parent community, including gene therapy, sibling support, navigating the healthcare system, managing behavior in CdLS, and GI health.

In addition, we were thrilled to see the scientific community come together once again for the 10th Biennial Scientific Virtual Symposium on Cornelia de Lange Syndrome, Cohesin, and Related Genes. With almost 50 experts from across the world in attendance, the symposium covered a wide range of topics, including sleep disturbances in CdLS, the impact of COVID-19 on individuals with CdLS, and behavior and anxiety triggers, among many others.

We were also excited to step back into in-person events with our first sponsored family gathering in New England since the pandemic began in March 2020. Over 40 individuals attended, and it was beautiful to see everyone connect and recharge in the magic of the CdLS community.

As we look ahead to the future, we are committed to taking a closer look at all aspects of our community to understand better how to serve you. Our ongoing listening tour allows us to learn about your joys and struggles and create programming and services that support you along the way. Again, thank you for your gifts of time, talent, and treasure, which power our dedication to service to every individual living with CdLS and their families.

Please join us in the following pages to see a review of the year 2022.

Best regards,
Bonnie

2022 Highlights



\$138,178
was raised at our two golf tournaments




CdLS Foundation
WELCOMED 113
new individuals
with CdLS

So many fantastic fundraisers happened this year. We could not have done it without the following:

**Mike Feehan's BackYard
Obstacle Course**
\$48,895

\$92,013
was raised by Team CdLS for
individuals with CdLS and their
families



271
Ask the Experts
questions were
answered

710
We connected with 710
individuals across the
United States



**ONE LOVE
ONE HEART**
\$11,064

Walgreens
SCANNABLE EVENT
\$14,321



“*At the end it's not about what you have or even what you've accomplished. It's about who you've lifted up, who you've made better. It's about what you've given back.*”

— Denzel Washington



TO OUR VALUED SUPPORTERS,



It has again been an honor to serve another year as the CdLS Board President and witness the continuous evolution of CdLS support and services. I am proud of the collaborative and inclusive spirit of the CdLS Foundation and what we accomplish through our united efforts. As always, we are immensely thankful to you, our supporters, for playing a pivotal role in what we can achieve each year.

In 2022, you were instrumental in helping

to support hallmark events such as our research symposium, family conference, and multidisciplinary clinics that bring our CdLS families together to receive vital education, resources, consultation, and connection. You have supported technological advances at the Foundation that allow for the most efficient support provided to our CdLS families. You have also supported the development of multilingual and accessible materials to reach more of our families.

As we look ahead to another year, we are excited to fulfill the goals and objectives that support our mission of reaching out, providing support, and giving hope to the nearly 4,000 CdLS families we serve. With your ongoing support, we continue to offer innovative ways to support the healthcare needs of our CdLS families, implement critical ways to support new and sustainable CdLS research efforts, provide special events that meet the needs of our CdLS families, and ensure that our families, staff, supporters, and volunteers feel a deep sense of

belonging in all that we do.

As we celebrate the endeavors of another year, I want to convey deep gratitude to each of you for the incredible impact and difference you make in our CdLS community. On behalf of our Board of Directors and the CdLS Foundation staff, we sincerely thank you for your contributions.

In service together,

Katherina N. Terhune

Katherina Nikzad-Terhune, Ph.D., LCSW
President of the Board of Directors

CELEBRATING DIFFERENCES LARGE AND SMALL

SUPPORT SERVICES THAT OFFER INCLUSION AND COMPASSION

THE REBIRTH OF IN-PERSON EVENTS

The CdLS Foundation began hosting in-person family-centric events for the first time since the pandemic. Families from the Northeast gathered in the fall for a New England Family Gathering in Massachusetts. Forty family members, friends, and individuals with CdLS were in attendance.

With the no in-person events, Family Service Coordinators (FSC) had the chance to re-envision gatherings. The new format provides opportunities for other family members, like siblings, to be more engaged and receive support services while in attendance.

Another critical in-person event that Family Service coordinated was the Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center (GBMC). Seven individuals with CdLS and 11 family members attended the clinic. Dr. Kline, the Foundation's Medical Director, hosts this exceptional free clinic for individuals with CdLS aged 12+ to attend with their families twice a year.

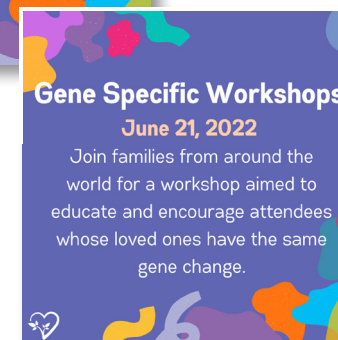
Attending a Foundation event can be exciting but challenging. Families may be hesitant to participate and planning to attend the event can be overwhelming. This is where the CdLS Foundation's Family Service Coordinators can assist. They share information about the event, what to expect, and how to register. They can also connect hesitant families with a veteran family (before the event) who will also be in attendance.



Families at the New England Family Gathering.



Social media graphics used to promote the event.



2022 CdLS FOUNDATION NATIONAL VIRTUAL FAMILY CONFERENCE

The 2022 National Family Conference was held virtually in mid-summer. The event's main goal was to meet the needs of as many families as possible; besides the Conference, the Foundation offered pre-conference workshops. These small workshops addressed topics of interest to specific portions of our CdLS community. For example, there was a workshop for families where CdLS is a new diagnosis, one for families with a child transitioning out of high school, and one for families of individuals prescribed behavioral health medications. These specialized workshops allowed small groups to discuss issues with professionals and other parents who have shared a similar journey.

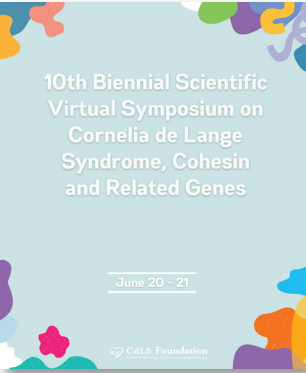
Nearly 200 families attended the 2022 virtual Conference. They learned how to best care for their loved ones with CdLS. Not only were attendees better equipped to face challenges throughout their loved one's lives, but they also left with a sense of belonging.

CELEBRATING DIFFERENCES LARGE AND SMALL CONTINUED...

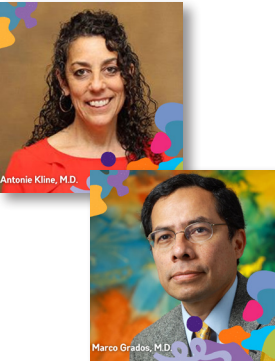
10TH BIENNIAL SYMPOSIUM ON CORNELIA DE LANGE SYNDROME AND COHESIN

The virtual Symposium featured lectures and formal discussions from clinicians and researchers on medical and educational issues facing individuals with the syndrome, findings that can impact the affected individuals and their families, and an update on basic science advances in cohesin biology and related genetic entities.

The Symposium was a unique way for over 45 researchers and clinicians to share their findings, further knowledge and form collaborations. It brought together new and seasoned researchers to present and publish current information related to CdLS and broaden their collective knowledge.



Symposium abstract booklet.

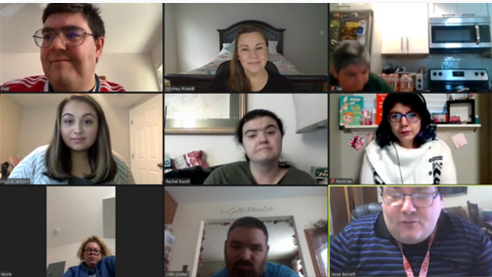


THE EMPOWERMENT TEAM

Every month, Family Service Coordinators facilitate a virtual therapeutic support group for adults with CdLS over the age of 18. It is attended regularly by eight to 10 individuals. Coordinators support attendees by helping them hone social skills in person and on social media, develop and practice self-advocacy skills, and navigate challenges at home, school, and work.

During 2022, the Empowerment Team shared their knowledge when speaking at the National Virtual Conference and the New England Family Gathering.

With the support of Family Service Coordinator Whitney Rinaldi, the group developed resources for themselves and the CdLS community, including *Get the Most Out of Your Provider Visit* and *Questions to Ask the Doctor*.

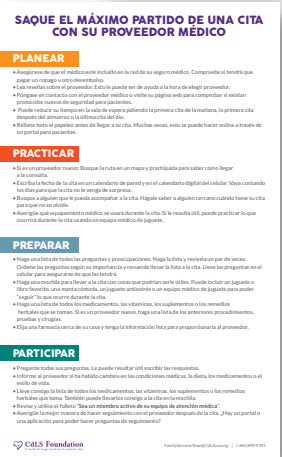
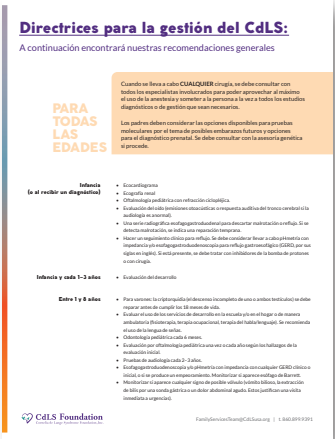


The Empowerment Team on a Zoom call.

MULTILINGUAL AWARENESS AND ADVOCACY MATERIALS FOR FAMILIES

The Family Service and Communication departments created various education and advocacy materials for the whole family. All items are available in English and Spanish.

- *The Gene Brochure* overviews the body systems affected and the findings you may see. It reviews CdLS's genetics, and the prevalence of individual gene changes.
- *Updated Management Guidelines* highlight routine screenings for people with CdLS by specific age groups, including infancy, early childhood, adolescence, and adulthood. At each age, individuals with CdLS will have certain healthcare needs.
- *Provider Letter* helps educate any new medical or therapeutic professionals about the diagnosis of CdLS, the genetics behind it, the prognosis, and where to go if they have any questions.
- *Get the Most Out of Your Visit to Your Provider* document helps you prepare for medical appointments and maximize your time with providers during a medical visit.
- *Questions to Ask the Doctor* form helps you and your loved one with CdLS feel more confident going to the doctor and asking questions. If they can go one day on their own, they learn how to be an active member of their healthcare team.



The Gene Brochure, Updated Management Guidelines, and Get the Most Out of Your Visit to Your Provider.

The Mistry Family



Kavin loves music and can sing in multiple languages. Music motivates, energizes, calms, and soothes him. He is my role model. At age 8, a geneticist felt Kavin had features of CdLS. We took him to the Children's Hospital of Philadelphia (CHOP). Doctors examined him. His blood work did not match any of the gene markers known for CdLS at that time. At 15, he was diagnosed with CdLS based on his physical characteristics. Years after that, we received a call from CHOP. Kavin's saved blood matched the *SMCIA* marker.

Working full-time while raising a family, the years flew by. But, in my mind, I always knew if I learned more, I could help more. The pandemic made that happen.

The transition from in-person to virtual education taught me that at-school Kavin was **utterly** different from home Kavin. At home, Kavin was funny and chatty and never stopped asking questions. At school, he was quiet, frozen, a deer in the headlights. When encouraged to speak, he opened his mouth, and no voice came out. His body was visibly tense.

In 2020, I began my Clinical doctorate in Speech-Language Pathology. I conducted a study on selective mutism in people with CdLS, what it looks like, and how to diagnose and treat this devastating disorder. Other communication challenges often present in those with CdLS can make it harder to diagnose selective mutism. My research led me to other parents who had not realized their child was suffering from selective mutism until participating in my study.

CdLS is like a box of 1,000 puzzle pieces. Despite all the research and knowledge, we are still missing puzzle pieces. With puzzle pieces missing, we have a life of trial and error. We need more research. We need more puzzle pieces.

If it takes a village to raise a child, our children need a city. That city can include siblings, family, friends, co-workers, and community members. As Kavin's needs change, our city helps us take one step at a time.

Our family has received unconditional support, understanding, and guidance from the CdLS Foundation over the years. As a parent and professional, I am grateful to have met professionals and families through the Foundation. You are now an integral part of our city.

I want to collaborate with the CdLS Foundation to spread awareness about selective mutism. I want to help other CdLS families get their children assessed and diagnosed earlier and receive timely help. We are truly blessed to be part of a world of angels living beside us.



Tasha Howland

On a memorable Tuesday in 2012, Peyton was born in the hospital, where our dedicated geneticist made his rounds that day. He recognized something special about her with one look and offered us a diagnosis. He jotted down the CdLS Foundation's website and encouraged us to connect with them immediately.

I got and continue to be involved with the CdLS Foundation because its solace is invaluable. **The assurance that there's a steadfast source of guidance and support throughout this journey makes it all manageable.** I recognize the immense dedication and compassion required to sustain a nonprofit, and I am committed to playing my role in ensuring the Foundation's longevity so it can continue to provide unwavering support to every CdLS family.



Whenever I think of Peyton, a radiant smile lights up my face and warms my heart. At just 11 years old, she possesses an infectious laugh and the kind of warm embrace that can melt even the coldest of hearts. Everyone who has the privilege of meeting her can't help but fall head over heels. As a big sister, she's nothing short of fantastic and keeps her younger brothers on their toes. Peyton's remarkable intelligence and unyielding determination shine through, and she's never shy about making her preferences known, even with her unique non-verbal communication style. She has imparted invaluable lessons to all of us, and I consider myself incredibly blessed to have been chosen as her mother.

Team CdLS Baltimore is an exceptional annual event during the Baltimore Running Festival, offering runners and walkers a unique opportunity to explore Baltimore City from a fresh perspective, all while championing the cause of CdLS. On Friday evening, we come together

for a heartwarming dinner to honor our dedicated runners and supporters. This event isn't just about raising funds; it's a beautiful occasion where families and friends gather, reconnect, and learn firsthand how their fundraising efforts drive the Foundation's vital work. People from the surrounding region rally behind our runners and walkers, making it an extraordinary and unifying experience.

Team CdLS plays a pivotal role in generating funds that directly and meaningfully impact families in need. Beyond the fundraising aspect, it is a beautiful opportunity for families in the region to come together, connect, and share their experiences.

The CdLS Foundation's focus on family support and research funding is the cornerstone of its mission. Through initiatives like Team CdLS, regional gatherings, and the National Conference, the Foundation fosters a vital network where families can unite and build a supportive community. Equally crucial is the commitment to research, which aims to deepen our understanding of CdLS, develop effective treatments, and enhance the quality of life for those living with CdLS.

I sincerely hope that the CdLS Foundation will persist in its efforts to broaden awareness of CdLS within the larger community, working to diminish the stigma, deepen understanding, and rally support for our incredible families. I also wish for the Foundation to forge ahead in unraveling the mysteries surrounding the causes and treatments for CdLS, ultimately translating this knowledge into enhanced therapies and improved quality of life for those living with CdLS. Lastly, I look forward to the day when the Foundation can once again bring together our CdLS community for valuable connections and shared experiences.

“Telling the story of CdLS and its impact on the community is so important to me.”

- Gabbie

STAFF SPOTLIGHT

GABRIELLE NADEAU

Gabrielle (Gabbie) has been at the CdLS Foundation since spring 2018. She began as the Communications Coordinator and is now the Communications Director. She oversees and writes most internal and external communications, including publications, e-blasts, social media posts, grants, invitations, and programs.

Since she began working at the Foundation, Gabbie's outlook on life has changed for the better. She says that the CdLS community has played a significant role in this transformation. When she arrived at the Foundation, she felt like she had a place at the table already. The staff, board members, and families welcomed her with open arms, and she has felt at home ever since.

One of the things Gabbie enjoys most about her job is bringing someone's story to life. She feels a sense of belonging when working with a family and hearing the passion in their voice.

She knows her writing can make a difference in someone's life, whether through Reaching Out or writing telling their story in a grant request. Telling the story of CdLS and its impact on our community and showing how the community rallies together are both so important to her.

When she's not working, Gabbie likes to propagate her many plants or read a good book at home. She also enjoys spending her free time with her husband and nieces.



Gabbie with her family, CdLS staff, and at Baltimore Running Festival.

Mike Feehan



Mike Feehan has been an integral part of the CdLS Foundation since 2009. He first turned to the Foundation for answers and support for his son Connor, who has CdLS. Since then, Mike has been an active volunteer, serving on the Finance Committee and the Board of Directors.

In 2009, Mike began running and participating in Mud Run events in Philadelphia to raise funds and awareness for the Foundation. Over time, the event has grown into something special. In 2020, due to the global pandemic, Mike decided to hold the event in his backyard and renamed it the "Feehan Backyard Obstacle Course." The event was successful, with 100% of the proceeds going directly to the CdLS Foundation.

In 2022, Mike and his family raised almost \$50,000 for the CdLS Foundation with their third annual Feehan Backyard Obstacle Course. With a goal of \$20,000, Mike began reaching out to family, friends, and colleagues in early May, requesting their support. The response he received was incredible.

The CdLS Foundation now holds the Feehan Backyard Obstacle Course as the gold standard for running a simple, inexpensive, and successful fundraising event. Thanks to the generosity of donors like Mike, the Foundation can continue to support individuals with CdLS and their families.

Mike's dedication to the Foundation is truly inspiring, and his efforts have significantly impacted the lives of individuals living with CdLS. We are grateful for donors like Mike, who continue to support our mission with their time, talent, and treasure.



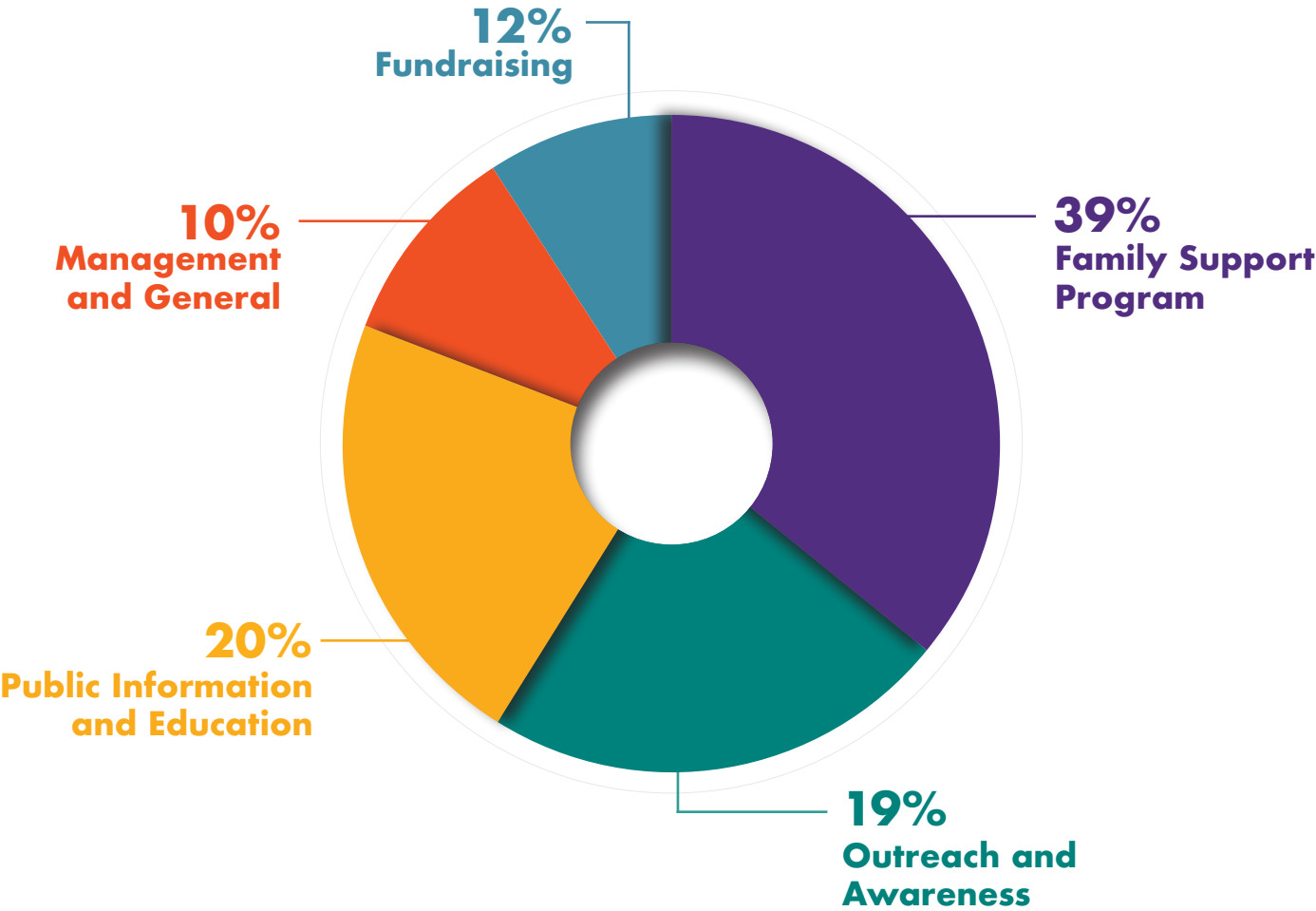
(Above) son Connor, (below) Mike, and fellow Feehan Backyard Obstacle Course participants.

2022 Audited Income & Expenses

INCOME	
Individual Donations	401,845
Corporations/Company Donations/ Clubs & Organizations	20,223
Foundations/Grants	41,624
Direct Mail	89,412
Gifts that Count – Memorial/Celebration	61,784
Special Events/ Third Party Fundraising	371,080
Federated Campaigns	52,131
Bequest	75,000
Restricted Nat’l Conference & Symposium	28,754
Restricted Research	10,860
Total Operating Revenue	1,152,713
Investment Net Income	32,915
Total Revenue	1,185,628

EXPENSES	
Program Services	
Outreach and Awareness	206,768
Research	-
Family Support Program	415,690
Public Information and Education	220,609
Total Program Services	843,067
Support Services	
Management and General	106,318
Fundraising	126,164
Total Support Service	232,482
Total Expenses	1,075,428
Net Assets, Beg of Year	3,311,087
Surplus/Deficit from Operations	(431,291)
Total Net Assets	2,879,796

2021 OPERATING EXPENSES



Your Gifts Made a Difference

We continued to feel some of the pandemic's affects in 2022, but thankfully our donors and sponsors sustained the organization in so many ways. It is due to the generosity and thoughtfulness of these supporters that the Foundation did not miss a step in continuing to offer the kind of support and resources that our families and the medical community have come to rely upon.

The next few pages in this report are dedicated to those who dug deep and gave in ways that truly touched our hearts. We are forever grateful to them.

All of the gifts that we receive are greatly appreciated, and there are multiple ways to give. Some of those ways help us to plan for the future of the organization, while others help us to sustain our day-to-day operations, as we know we can count on those funds on a regular basis. As a result, we wish to show special recognition to the following:

VISIONARIES CIRCLE - IMPACTFUL GIVING

As our most distinguished donors, the members of our Visionaries Circle have made generous donations totaling more than \$100,000 for the year. Their incredible commitment to the CdLS Foundation has had an impact not only on the day to day operations of the Foundation, but also has given us the opportunity to plan for the future success of the organization in serving our families. We owe a debt of gratitude to these very special donors, who are the CdLS Foundation’s Visionaries:

Wendy Miller, Esq. and Andrew Miller

LEGACY LEADERS - PLANNED GIVING

These forward-thinking donors have made a bequest or other planned gift to support the CdLS Foundation’s future, leaving a legacy for generations to come. We are extremely grateful for our CdLS Foundation Legacy Leaders:

Gayle McCue (deceased) and Steve McCue

○ ○ ○ SUSTAINERS CIRCLE—RECURRING GIFTS ○ ○ ○

These thoughtful donors make a big impact by contributing a set amount either weekly or monthly, helping to sustain the CdLS Foundation with gifts that we know we can count on regularly. Some donate online by selecting the “recurring” option, while others donate through direct deposit from their paychecks, or simply send in payment. For information on becoming part of our Sustainers Circle contact the Foundation.

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Thank you to our generous donors. You helped us serve nearly 700 individuals including over 50 medical and educational professionals in 2022.

Legacy Leaders (Planned Giving)

Gayle McCue (deceased) and Steve McCue

Visionaries Circle (\$100,000+)

Wendy Miller, Esq. and Andrew Miller

Heroes Club (\$20,000—\$99,999)

Barbara and Doug Gaines
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CdLS Leaders (\$10,000—\$19,999)

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Whether they are supporting one of our special events, providing grant funding or matching employee donations, we are very grateful for our incredible business and organization sponsors who partner along with us in our important mission to serve our families by their generous giving.

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Thank you for helping
individuals and families
affected by CdLS.

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Michele Lambert, M.D., Hematologist
Soma Jyonouchi, M.D., Immunology
Clair Francomano, M.D.,
Internal Medicine, Genetics
Katherina Terhune, Ph.D., LCSW,
Mental Health
Soma Das, Ph.D., FACMG, Molecular Genetics
Anne Calof, Ph.D., Neurodevelopmental Biology
Ingrid Barone, R.N., Nursing
Kari Cunningham-Rosvik, APRN,
Nurse Practitioner
Christine Ackermann, M.S., O.T.,
Occupational Therapy
Joann Fleckenstein, M.S., O.T.,
Occupational Therapy

Aaron Zuckerberg, M.D.,
Pediatric Anesthesia, PICU
Jeff Rockow, M.D., Pediatric Cardiology
Richard Mungo, D.D.S., Pediatric Dentistry
Joni Rampolla, L.D., Pediatric Dietetics
Loretta Gore-Harvey, R.D., L.D.N.,
Pediatric Dietetics
Carol Potter, M.D., Pediatric Gastroenterology
Kathleen Loomes, M.D.,
Pediatric Gastroenterology
Lynette Gillis, M.D., Pediatric Gastroenterology
Michael Asike, M.D., Pediatric Gastroenterology
Kristin Baranano, M.D., Pediatric Neurology
Lynne Kerr, M.D., Pediatric Neurology
Siddharth Srivastava, M.D., Pediatric Neurology
Alex Levin, M.D., Pediatric Ophthalmology
Claire Shannon, M.D.,
Pediatric Orthopedic Surgery
Stacey Ishman, M.D., Pediatric Otolaryngology
Katherine Farr, D.P.T., Physical Therapy
Amy Metrena, M.S.P.T., Physical Therapy
Dorothy K. Grange, MD, Professor of
Pediatrics, Genetics and Genomic Medicine
Mark Kliewer, M.D., Radiology
Richard Haaland, Ph.D., Research

Mary Levis N.C.S.P., School Psychology
Michelle Champion, M.Ed., Special Education
Cheri Carrico, Ph.D., CCC-SLP,
Speech-Language-Feeding
Patti Caudill, M.S., CCC-SLP;
Speech-Language-Feeding
Nancy Mathis, M.S., CCC-SLP,
Speech-Language Pathology
Ming-Hsien Wang, M.D., Urology



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

30 Tower Lane, Suite 400

Avon, CT 06001-3681

800.753.2357 • www.CdLSusa.org